

Senate Bill No. 537

CHAPTER 1011

An act to add and repeal Section 125001 of the Health and Safety Code, relating to health, and making an appropriation therefor.

[Approved by Governor September 29, 1998. Filed
with Secretary of State September 30, 1998.]

LEGISLATIVE COUNSEL'S DIGEST

SB 537, Greene. Genetic diseases: expanded newborn screening program.

Existing law, the Holden-Moscone-Garamendi Genetically Handicapped Person's Program, requires the Director of Health Services to establish and administer a program for the medical care of persons with genetically handicapping conditions, and requires the department to establish a rate structure for physician and surgeon reimbursement, and to establish an enrollment fee.

Existing law requires the State Department of Health Services to establish a genetic disease unit to promote a statewide program of information, testing, and counseling services and creates the continuously appropriated Genetic Disease Testing Fund for that purpose and into which fees obtained for the performance of these tests are deposited.

This bill would require the department to establish a program to provide extended newborn genetic screening services for persons who elect to have, and pay for, the additional screening, and would require the department to charge a fee not to exceed the costs of these additional screenings, that would be deposited into the Genetic Disease Testing Fund, thus constituting an appropriation.

The bill would authorize, for the fiscal year 1998-99, the sum of \$1,000,000 to be expended by the department from the unencumbered reserves of that fund for purposes of the program.

This bill would require the department to report to the Legislature by June 30, 2000, and would repeal all of its provisions on January 1, 2002.

Appropriation: yes.

The people of the State of California do enact as follows:

SECTION 1. Section 125001 is added to the Health and Safety Code, to read:

125001. (a) The Legislature finds and declares all of the following:



(1) California requires testing at birth for certain genetic diseases or conditions.

(2) Technology called tandem mass spectography is now available that would permit testing for many more genetic diseases or conditions.

(3) Many of the additional tests can be made from the same blood sample at costs of between eighteen dollars (\$18) and twenty dollars (\$20).

(4) It is the intent of the Legislature that a program for testing services and training be initiated as expeditiously as possible utilizing laboratory services experienced in tandem mass spectography.

(b) The department shall establish a program for genetic disease testing, and may provide laboratory testing facilities or contract with any laboratory that it deems qualified to conduct testing or provide necessary treatment with qualified specialists. The program shall provide extended newborn genetic screening services under the Hereditary Disorders Act for persons who elect to have, and pay, for the additional screening.

(c) The department shall charge a fee for the additional screening not to exceed the costs of the additional screening. Any fees collected to support the program shall be deposited in the Genetic Disease Testing Fund.

(d) The additional genetic conditions for which testing may be provided under this program may include, but need not be limited to, any of the following:

- (1) Adenosine deaminase deficiency.
- (2) Arginase deficiency.
- (3) Biotinidase deficiency.
- (4) Congenital adrenal hyperplasia.
- (5) Cystic fibrosis.
- (6) Duchenne-Becker muscular dystrophy.
- (7) Glucose-6-phosphate dehydrogenase.
- (8) Homocystinuria.
- (9) Maple Syrup Urine Disease.
- (10) Acute neonatal citrullinemia.
- (11) Pyroglutamic aciduria.
- (12) Medium chain ACYL-COA dehydrogenase and other fatty acid oxidation disorders.
- (13) Methylmalonic acidemias.
- (14) Propionic acidemia.
- (15) Isovaleric acidemia.
- (16) Glutaric acidemia, type I and type II, and other organic acid disorders.

(e) The department shall report to the Legislature regarding the progress of the program by June 30, 2000. The report shall include the costs for screening, followup, and treatment, as compared to the costs and morbidity averted for each condition tested for in the program.

(f) This section shall remain in effect only until January 1, 2002, and as of that date is repealed, unless a later enacted statute, that is enacted before January 1, 2002, deletes or extends that date.

SEC. 2. (a) (1) In order to support the cost of the program provided for in Section 125001 of the Health and Safety Code, as contained in Section 1 of this act, the sum of one million dollars (\$1,000,000) is hereby authorized for the fiscal year 1998–99 to be expended by the State Department of Health Services from the unencumbered reserves of the Genetic Disease Testing Fund, which shall cover the cost of equipment, personnel, consultant contracts, and out-of-state travel related to conducting the program.

(2) The expenditure of moneys from this fund for these purposes shall not be subject to Chapter 2 (commencing with Section 10290) of Part 2 of Division 2 of the Public Contract Code. The State Department of Health Services shall provide the Department of Finance with documentation justifying that equipment and services have been obtained at the lowest cost and consistent with technical requirements for a comprehensive high-quality program.

(b) It is the intent of the Legislature that, for subsequent fiscal years, authorization be provided for the use of moneys from the Genetic Disease Testing Fund to cover the cost of the program provided for in Section 125001 of the Health and Safety Code, as contained in Section 1 of this act.

SEC. 3. The Legislature finds and declares that timely implementation of the program provided for in Section 125001 of the Health and Safety Code, as contained in Section 1 of this act, requires expeditious regulatory and administrative procedures to obtain the most cost-effective testing equipment and testing services contracts.

